

# Palliative care in patients with severe mental illness

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Severe, persistent mental illness (SPMI) presents a unique but not uncommon challenge to palliative care providers across many practice settings, and potentially at every stage of advanced illness. The cases below describe 2 patients with severe mental illness, both of whom had been admitted to inpatient forensic psychiatry units for a number of years, who presented to an outpatient palliative care clinic. This article seeks to explore the barriers faced by these patients in accessing palliative care, and the challenges faced by providers in offering adequate supports to ensure equitable and appropriate care for both symptom management and advance care planning.

## Case 1

A 49-year-old Inuit woman with metastatic breast cancer presented to the outpatient palliative care

clinic after referral from her medical oncologist for a goals-of-care discussion and advance care planning. She was initially diagnosed with estrogen receptor- and progesterone receptor-negative, human epidermal growth factor receptor 2-equivocal right-sided breast cancer, and treated with mastectomy and axillary lymph node dissection. A year later, she developed recurrent metastatic disease to the right axillary lymph node and pulmonary nodules, and multiple bone lesions on the left iliac crest, spine, and right sacrum. She received radiation (30 Gy) to the left pelvis, left sacroiliac joint, and lymph nodes. After her disease progressed while taking paclitaxel, she was offered capecitabine, which she was currently declining for unknown reasons.

Concurrent with her oncologic treatment, this woman had been admitted to an inpatient forensic

## Editor's key points

- ▶ In managing patients with advanced illness with comorbid severe, persistent mental illness, care must be taken to ensure that services are provided in a manner that recognizes inherent potential difficulties in assessing patient capacity and goals. Engaging with social workers, psychiatric nurses, and psychiatrists before, during, and after patient encounters can ensure that clinical visits are tailored to accommodate the patient's psychosocial needs.
- ▶ For patients who might have behavioural issues that disrupt treatment, it can help to book appointments at times of day that allow minimal disruption, noise, and crowding. Allowing ample time to account for lateness optimizes care and can also assist in building rapport with patients.
- ▶ The social environment might inhibit access to care, which can be alleviated by ensuring that cultural and language interpreters are used consistently and appropriately, and by collecting collateral information from the patient's community and support networks; this can also help offset issues with poor health literacy. Providing resources to patients to navigate an increasingly complex health system is valuable, such as transportation to radiation treatments.

## Points de repère du rédacteur

- ▶ Dans la prise en charge de patients en stade avancé de la maladie et souffrant d'un problème concomitant de santé mentale persistant et grave, il y a lieu d'assurer que les services sont fournis de manière à reconnaître les difficultés potentielles inhérentes à l'évaluation de l'aptitude et des objectifs du patient. La participation de travailleurs sociaux, d'infirmières en psychiatrie et de psychiatres avant, durant et après les rencontres avec le patient peut faire en sorte que les visites cliniques soient adaptées à ses besoins psychosociaux.
- ▶ Lorsque les patients sont susceptibles d'avoir des problèmes comportementaux qui perturbent le traitement, il peut être utile de leur donner des rendez-vous à des moments de la journée où il y a moins de dérangements, de bruits et d'achalandage. Pour optimiser les soins et faciliter l'établissement d'un lien avec le patient, il est aussi conseillé d'accorder amplement de temps pour compenser les retards.
- ▶ L'environnement social peut entraver l'accès aux soins. Pour atténuer ce problème, il faut veiller à recourir, de manière cohérente et appropriée, à des interprètes culturels et linguistiques, et recueillir des renseignements connexes auprès de la communauté et des réseaux de soutien du patient, ce qui peut aussi contribuer à compenser le manque de littératie sur le plan de la santé. L'offre de ressources aux patients pour naviguer dans un système de santé de plus en plus complexe se révèle une aide précieuse, par exemple le transport pour subir la radiothérapie.

psychiatric unit in Toronto, Ont, for the past 9 years. She had previously lived in Nunavut and had no family or community social supports in Toronto. Her psychiatric history was relevant for antisocial personality disorder, schizoaffective disorder, delusional disorder, and borderline personality disorder. She also had a previous history of alcohol use disorder before her psychiatric admission.

Concerns were raised by her medical oncology, hospitalist, and psychiatric teams regarding her capacity to make decisions regarding cancer treatment, given her paranoid and delusional thought processes. To facilitate a thorough capacity assessment, the patient's social worker and nurse were asked to accompany the patient to the palliative clinic appointment. Additionally, the palliative clinic social worker and an Aboriginal patient navigator were referred to assess the patient. The assessment included exploration of the patient's illness understanding, values, and goals for treatment, including wishes for care at the end of life. This revealed that the patient wished to return home to Nunavut to die and, therefore, did not want further treatment of her cancer. With the assistance of the Aboriginal patient navigator, further discussion was completed around traditional healing and the patient's strong wish to return to her own community at the end of life. It became clear during the course of this assessment that the patient had carefully considered the potential risk and side effects of chemotherapy, and weighed this thoughtfully with her wish to die in her own community, with the comfort of her loved ones around her.

Recommendations regarding management of symptoms at the end of life were made and arrangements were made for the patient to be transferred to a Nunavut hospital on compassionate grounds. The patient died 5 weeks later, in the company of her family.

## Case 2

A 50-year-old woman presented to the outpatient palliative care clinic, referred by her hospitalist physician. She had been admitted to an inpatient forensic psychiatry unit for 5 years. She was initially diagnosed 3 years previously with estrogen receptor- and progesterone receptor-negative, human epidermal growth factor receptor 2-equivocal right-sided invasive ductal carcinoma, and treated with modified radical mastectomy of the right breast. She had declined chemotherapy but accepted hormone therapy. She was treated with tamoxifen until her disease progressed 2 years later. She had developed metastatic disease to her lumbar spine and pelvis, which was treated with radiation. She then developed a compression fracture to the T1 vertebra, extensive vertebral metastases, and pathologic fractures to the right inferior and superior pubic rami. She was referred by her hospitalist physician for

assessment of pain related to the recent development of metastasis to the left humerus. Her psychiatric history was relevant for bipolar-type schizoaffective disorder.

On further review, this patient had a history of missed appointments; sporadically declining bloodwork, imaging, and radiation therapy; and occasional aggressive and confrontational behaviour toward providers. She would often become agitated during appointments and would leave part way through encounters. She consistently declined any medication administered intravenously or subcutaneously. As a result, her pain management secondary to bony metastases had been difficult to optimize.

The patient's visit was scheduled as the last appointment of the day to allow ample time. When seen, the patient was accompanied by her psychiatric social worker and nurse. On initiation of the clinical encounter, the patient demonstrated limited ability to cope with the difficult conversations around her illness, and she left the clinic after a few minutes. On discussion with her psychiatric team, it was decided to allow her some time to process the visit, with the opportunity to return if she wished. She returned 20 minutes later, and the visit resumed. On discussion of her symptoms and goals of care, the patient demonstrated adequate illness understanding and expressed her hope that her pain would be better controlled. She agreed to re-referral to radiation oncology and recommendations for an analgesic regimen. She was transferred to radiation oncology, and it was emphasized that sufficient time be allowed for the encounter and for her to be accompanied by her regular social worker or psychiatric nurse. She was able to receive treatment to her left humerus, which markedly improved her pain.

## Discussion

These cases illustrate the considerable barriers faced by patients with SPMI in accessing comprehensive palliative care. They also emphasize the importance of accommodation for patients with complex mental health issues. A systematic review on palliative care for people with SPMI highlights the lack of empirical studies that could guide how to optimize care of these patients not only in outpatient palliative settings, but also in inpatient, home, and hospice care.<sup>1</sup> The presence of illnesses that carry substantial morbidity, including personality disorders, schizophrenia, and substance use disorders, might directly and indirectly affect access to and provision of palliative care.<sup>2</sup>

These direct and indirect effects are well demonstrated in these 2 cases. The first case illustrates how patient autonomy to make medical decisions might be limited by physician perception of capacity in patients with SPMI. Advance care plans and decisions around preferred place of death were delayed in this instance,


given concerns regarding the patient's lack of capacity owing to severe paranoid thoughts and delusions. This was further complicated by the patient's isolation from her family and cultural community group, preventing her from discussing treatment preferences with loved ones. The inclusion of a cultural interpreter (in this case an Aboriginal patient navigator) can allow providers to better understand the patient's cultural context and assist in capacity assessments. Indeed, it became clear through repeated discussions that the patient's decision to stop systemic therapy was an informed choice in keeping with her cultural and spiritual beliefs, despite the known severity of her mental illnesses. Thorough goals-of-care discussion including this information allowed for advance care planning and the patient was transferred back to her community for end-of-life care. Early and frequent palliative care involvement in this patient's care was therefore necessary to ensure timely conversations around these important topics.

The second issue, which arose from the second case, was palliative care providers' comfort and experience in managing patients with SPMI. Behavioural issues had prevented the patient from accessing radiation therapy, given the providers' difficulties in optimizing an environment for the patient's comfort. Ensuring that a psychiatric nurse or social worker is present can help facilitate these encounters and give palliative care providers assistance with addressing the mental health needs of the patient to best provide comprehensive care.<sup>3</sup>

Considering these 2 cases together, there were several specific tools and approaches that were used that facilitated the delivery of equitable and comprehensive palliative care in patients with SPMI. Engaging with social workers, psychiatric nurses, and psychiatrists before, during, and after patient encounters can ensure that clinical visits are tailored to accommodate the psychosocial needs of the patient. Booking appointments at times of day that will allow minimal disruption, noise, crowding, and ample time to account for lateness optimizes care and can also assist in building rapport

with patients. Ensuring that cultural and language interpreters are used consistently and appropriately, as well as collecting collateral information from the community and support networks of the patient, also helps offset issues with poor health literacy. Finally, providing resources to patients to navigate an increasingly complex health system is valuable, such as transportation to radiation treatments or a volunteer to accompany patients during long chemotherapy sessions. In resource-limited settings, innovative solutions could be considered, such as peer support groups during treatments and exploration of video- or teleconferencing tools to provide access to oncologic and palliative consultation in more geographically remote areas.

## Conclusion

In managing patients with advanced illness with comorbid SPMI, care must be taken to ensure that services are provided in a manner that recognizes inherent potential difficulties in assessing patient capacity and goals, behavioural issues that might disrupt treatment, and the social environment that might inhibit access to care. Further research is needed on collaborative models to better facilitate these encounters. 

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### Competing interests

None declared

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### References

1. Woods A, Willison K, Kington C, Gavin A. Palliative care for people with severe persistent mental illness: a review of the literature. *Can J Psychiatry* 2008;53(11):725-36.
2. Butler H, O'Brien AJ. Access to specialist palliative care services by people with severe and persistent mental illness: a retrospective cohort study. *Int J Ment Health Nurs* 2018;27(2):737-46. Epub 2017 Jul 10.
3. Baker A. Palliative and end-of-life care in the serious and persistently mentally ill population. *J Am Psychiatr Nurses Assoc* 2005;11(5):298-303.

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